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Public Awareness and Knowledge Gaps Regarding Childhood Hemophilia in Tabuk City: A Cross-Sectional Study

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Abstract Objectives: Hemophilia in children is among the most prevalent and severe congenital coagulation factor deficiency disorders. This condition is characterized by a lifelong predisposition to bleeding, which may be spontaneous or disproportionate to trauma, resulting from the absence of clotting factors. This study aimed to assess public awareness regarding various aspects of pediatric hemophilia among residents of Tabuk City, Saudi Arabia. **Methods:** A cross-sectional, questionnaire-based survey was conducted involving 402 adult Saudi males and females residing in Tabuk City, representing a range of age groups and educational backgrounds. The questionnaire included 15 statements aimed at evaluating various aspects of hemophilia-related knowledge. Knowledge scores were calculated by assigning one point for each correct response, while incorrect or "do not know" answers were given a score of zero. **Results:** The study showed that 45.3% of participants had no prior knowledge of hemophilia. Only 12.7% demonstrated good knowledge, while 17.7% and 24.4% fell into the low and fair knowledge categories, respectively. Overall, public awareness of pediatric hemophilia was suboptimal. There were no statistically significant differences based on age, sex, or education level." **Conclusions:** There is a significant deficiency in public knowledge regarding childhood hemophilia among the population of Tabuk City. These findings underscore the necessity of implementing comprehensive public health initiatives, such as educational programs and awareness campaigns to enhance understanding and early recognition of this serious bleeding disorder.

Key Words Children, hemophilia, public awareness, knowledge gaps, Saudi Arabia

INTRODUCTION

Hemophilia in children is an inherited X-linked bleeding disorder characterized by a lack or deficiency of clotting factors, resulting in prolonged bleeding episodes. Hemophilia A arises from a deficiency in factor VIII (FVIII), while hemophilia B and C result from a shortage of factor IX and XI, respectively. They present with similar clinical symptoms; therefore, specialized factor assays are required to accurately distinguish and confirm the diagnosis [1].

Infants and young children face distinct issues and challenges compared to older children and adults, although bleeding episodes continue to be the main symptom used for diagnosis [2]. Bleeding can impact joint and muscle health and poses serious health risks such as spontaneous internal bleeding, joint stiffness, and intracranial hemorrhage [3,4].

The global incidence of hemophilia A and B is estimated to be approximately 1 in 5,000 and 1 in 30,000 live births, respectively, with a higher occurrence in males than females [5]. Consequently, the worldwide number of individuals with hemophilia is projected to exceed 1.1 million, with around 400,000 likely experiencing severe forms of the disorder [6]. Hemophilia A may be more prevalent in the Gulf region due to high rates of consanguineous marriage, which can indirectly increase the number of female carriers and the risk of transmission by promoting genetic homogeneity [7,8].

Hemophilia is typically treated with costly lifelong infusions of clotting factors, with annual treatment costs reaching up to $450,000 in developed countries [9]. In contrast, patients in developing nations often lack access to regular treatment, leading to severe complications and

reduced quality of life [10]. Despite progress in gene therapy for hemophilia, challenges persist, including immune responses, genotoxicity, and long-term effectiveness. Additionally, children are often ineligible for treatment due to concerns about liver development and transgene durability [9,11].

Timely diagnosis and effective management are essential for enhancing the health and quality of life of individuals with hemophilia. Low awareness and misunderstandings about hemophilia, especially its genetic basis, available therapies, and concerns related to physical activity, can lead to delayed diagnosis, inadequate care, and lifelong disabilities [12]. Hence, raising public awareness is vital for early symptom recognition, reducing stigma, and promoting prompt access to treatment [13,14].

Only one study previously evaluated awareness of hemophilia in Saudi Arabia and showed limited awareness and understanding of childhood hemophilia [15]. Therefore, this study aimed to assess the level of public awareness and identify knowledge gaps regarding childhood hemophilia in Tabuk City to guide the establishment of targeted educational initiatives and community-based programs.

METHODS

Study Design, Setting, and Date

This cross-sectional observational study was conducted in Tabuk, Saudi Arabia, over 3 months from March to May, 2025.

Inclusion and Exclusion Criteria

The study included all adult males and females aged 18 years and older residing in Tabuk City who voluntarily consented to complete the questionnaire. Individuals were excluded if they resided outside Tabuk City, were employed in medical or paramedical professions, declined participation, or submitted incomplete survey responses.

Sampling and Sample size Calculation

A simple random sampling technique was employed to recruit participants for the study. The sample size was calculated using an online sample size calculator, based on an estimated population of 624,000 adults residing in Tabuk City, as reported by the Saudi Census. With a 95% confidence level, a 5% margin of error, and a 50% response distribution, the minimum required sample size was determined to be 385 participants.

Data Collection

The data were gathered using a structured, online questionnaire in Arabic, adopted from a previous study [16]. The questionnaire consisted of two main sections. The first section captured the participants' sociodemographic characteristics, including age, gender, education levels, in addition to a question about familiarity with someone who has hemophilia and the type of this relationship. The second section included 15 statements designed to assess participants' knowledge of various aspects of childhood hemophilia.

For the calculation of the knowledge score, each correct answer was assigned one point, while incorrect or "do not know" responses received zero points. The total knowledge score ranged from zero to 15. Participants scoring zero were classified as having "no knowledge," those scoring between one and six were categorized as having "low knowledge", scores from seven to 11 indicated "fair knowledge", and scores between 12 and 15 represented "good knowledge" of childhood hemophilia.

Participants were invited to participate through WhatsApp. An online link to the questionnaire was sent to those who agreed to participate, and they completed the survey independently.

Statistical Analysis

Data was tabulated and analyzed using the Statistical Package for the Social Sciences (SPSS) version 27 (IBM Corp., Armonk, NY, USA). Qualitative variables were summarized as frequencies and percentages. The associations between participants' sociodemographic characteristics and their knowledge levels were assessed using the Chi-Square test. When expected cell frequencies were below 5, the Fisher-Freeman-Halton Exact test was applied. P values less than 0.05 were considered statistically significant.

Ethical Considerations

The Research Ethics Committee of the University of Tabuk approved this study with an assigned number (UT-592-283-2025) To ensure confidentiality, each participant was given a unique code, and no personal identifiers or names were recorded. Before participation, informed consent was obtained following a thorough explanation of the study's aim and procedures.

RESULTS

This study included a total of 402 participants. Most (78.4%) of them were female, while males accounted for 21.6%. The participants' ages ranged from 18 to more than 50 years, with the largest age group being 21–29 years (35.6%), followed by those aged 40–49 years (19.9%) and 50 years or more (17.9%). Regarding education level, most participants held a university degree or higher (79.4%). When asked about familiarity with hemophilia, only 34 (8.5%) reported knowing someone affected by the condition. Among those who knew someone with hemophilia, the most commonly reported relationship was a son of a relative (3.7%), followed by the son of a friend (2.2%). Direct familial relationships, such as having a son (0.2%) or cousin (0.2%) with hemophilia, were occasional (Table 1).

Table 2 shows the participants' responses to inquiries about their knowledge of childhood hemophilia. There were several knowledge gaps across all the assessed aspects. For most questions, the majority of respondents selected "do not know," with percentages ranging from 55.5% to 72.6%. Only 29.1% correctly identified brain bleeding as a complication of hemophilia. Similarly, just 22.4%

Table 1: Sociodemographic profile of the study participants (N = 402)

Parameters		N = 402	%
Gender	Female	315	78.4%
	Male	87	21.6%
Age, years	18-20	47	11.7%
	21-29	143	35.6%
	30-39	60	14.9%
	40-49	80	19.9%
	50 or more	72	17.9%
Education level	Uneducated	3	0.7%
	Primary	7	1.7%
	Intermediate	9	2.2%
	Secondary	64	15.9%
	University or higher	319	79.4%
Do you know someone with hemophilia?	No	368	91.5%
	Yes	34	8.5%
If the answer to the previous question is yes, what is the relationship between you and the affected person?	Son of a relative	15	3.7%
	Son of a friend	9	2.2%
	Son	1	0.2%
	Cousin	1	0.2%
	Other	8	2.0%

N: number, %: Percentage

Table 2: Participants' responses on knowledge about childhood hemophilia (N = 402)

Questions		N=402	%
Brain bleeding is one of hemophilia complication	True*	117	29.1%
	False	10	2.5%
	Not know	275	68.4%
Until now, there is no cure for hemophilia	True*	90	22.4%
	False	44	10.9%
	Not know	268	66.7%
Brothers of hemophilia patients could have the same disease	True*	118	29.4%
	False	29	7.2%
	Not know	255	63.4%
Hemophilia is an infectious disease	True	20	5.0%
	False*	152	37.8%
	Not know	230	57.2%
In Hemophilic patient, blood are not clotting or need more time than normal	True*	159	39.6%
	False	7	1.7%
	Not know	236	58.7%
Hemophilia are not lifelong disease	True	46	11.4%
	False*	102	25.4%
	Not know	254	63.2%
The treatment of hemophilia is giving the recombinant factor for blood clotting	True*	129	32.1%
	False	11	2.7%
	Not know	262	65.2%
Patient with hemophilia are not easily bruising when stumble or falling	True	34	8.5%
	False*	134	33.3%
	Not know	234	58.2%
Sports with hard physical contact such as soccer, hockey and wrestling are not safe for patient with hemophilia	True*	158	39.3%
	False	21	5.2%
	Not know	223	55.5%
If injured, the first aid management is compression with ice	True*	87	21.6%
	False	23	5.7%
	Not know	292	72.6%
The patient with hemophilia usually don't have any medical family history with hemophilia	True	51	12.7%
	False*	100	24.9%
	Not know	251	62.4%
Patient with hemophilia still could have good mental health and development	True*	103	25.6%
	False	35	8.7%
	Not know	264	65.7%
Tooth extraction could cause massive bleeding in hemophilic patients	True*	151	37.6%
	False	11	2.7%
	Not know	240	59.7%
Hemophilia couldn't cause death	True	26	6.5%
	False*	100	24.9%
	Not know	276	68.7%
The joint of hemophilic patients could be stiff because of untreated bleeding	True*	109	27.1%
	False	12	3.0%
	Not know	281	69.9%

*: Indicates the correct answers

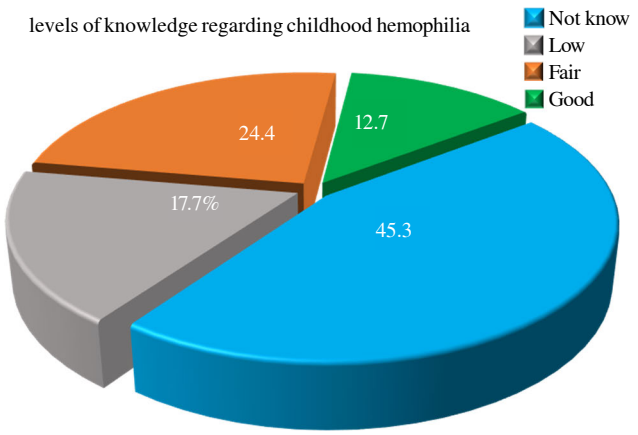

Figure 1: Participants' levels of knowledge regarding childhood hemophilia

recognized that there is currently no cure for hemophilia. When asked whether brothers of hemophilia patients could have the same disease, only 29.4% responded correctly. Only 37.8% correctly identified hemophilia as a non-infectious disease. Regarding the nature of blood clotting in hemophilic patients, 39.6% correctly acknowledged the delay in clotting. Only 25.4% correctly reported that hemophilia is a lifelong condition, 32.1% knew that the hemophilia treatment involves administering recombinant clotting factors, and 33.3% correctly recognized that patients with hemophilia are easily bruised when stumbling or falling. Concerning physical activity, 39.3% correctly identified that contact sports such as soccer, hockey, and wrestling are unsafe for individuals with hemophilia. Regarding appropriate first aid measures for hemophilia-related injuries, only 21.6% correctly indicated that compression with ice is the proper initial management. Additionally, just 24.9% correctly recognized that hemophilia often has a medical family history, 25.6% knew that patients with hemophilia can still achieve good mental health and development, 37.6% recognized that tooth extraction could cause massive bleeding in hemophilic patients, and 24.9% correctly understood that hemophilia can be fatal.

Furthermore, only 27.1% were aware that untreated bleeding can lead to joint stiffness in hemophilic patients.

Figure 1 illustrates that 45.3% of participants did not know about childhood hemophilia, while only 12.7% demonstrated good knowledge, with the remainder falling into low (17.7%) and fair (24.4%) categories.

Table 3 shows the associations between sociodemographic variables and knowledge levels about childhood hemophilia. Each of sex, age, and education level was not significantly associated with knowledge levels (All p-values >0.05). However, knowing someone with hemophilia was significantly associated with higher knowledge levels ($p<0.001$).

Table 3: Associations of sociodemographic variables with Knowledge levels about hemophilia in children

Parameters		Knowledge levels								P-Value
		Not know		Low		Fair		Good		
		N	%	N	%	N	%	N	%	
Sex	Female	149	81.9%	53	74.6%	75	76.5%	38	74.5%	0.469
	Male	33	18.1%	18	25.4%	23	23.5%	13	25.5%	
Age, years	18-20	20	11.0%	9	12.7%	13	13.3%	5	9.8%	0.054
	21-29	47	25.8%	30	42.3%	40	40.8%	26	51.0%	
	30-39	34	18.7%	8	11.3%	11	11.2%	7	13.7%	
	40-49	45	24.7%	14	19.7%	14	14.3%	7	13.7%	
	50 or more	36	19.8%	10	14.1%	20	20.4%	6	11.8%	
Education level	Below university	36	19.8%	14	19.7%	20	20.4%	12	23.5%	0.946
	University or higher	146	80.2%	57	80.3%	78	79.6%	39	76.5%	
Do you know someone with hemophilia?	No	181	99.5%	62	87.3%	82	83.7%	43	84.3%	<0.001*
	Yes	1	0.5%	9	12.7%	16	16.3%	8	15.7%	

*Significant at p<0.05

DISCUSSION

In this study, the assessment of public knowledge about childhood hemophilia in Tabuk City revealed critical gaps in awareness and understanding. Nearly half (45.3%) did not know about the condition, and only a small proportion (12.7%) showed good understanding. The remaining expressed either low (17.7%) or fair (24.4%) knowledge.

The study explored a consistent deficiency in public understanding of key aspects of childhood hemophilia. For most questions, the majority of respondents selected "do not know," with percentages ranging from 55.5 % to 72.6%. Awareness of symptoms and severity was low, with just 37.8% knowing that hemophilia is non-infectious, 33.3% identifying easy bruising, and 24.9% acknowledging that it can be fatal. Knowledge about treatment and management was similarly lacking, as only 32.1% knew about recombinant clotting factors, 21.6% understood correct first aid measures, and 25.4% recognized hemophilia as a lifelong condition. Likewise, correct Knowledge about serious complications of hemophilia in terms of brain bleeding (29.1%), and inheritance (24.9%) was deficient.

The detected knowledge gaps regarding childhood hemophilia in Tabuk City can be attributed to several factors. One major reason is the limited public health education and awareness campaigns focused on rare genetic conditions like hemophilia. Since the disorder is not commonly encountered by the general public, it often receives less attention compared to more prevalent health issues. Additionally, low health literacy levels and a lack of accessible, easy-to-understand information contribute to poor public understanding [12,14,17]. Moreover, the role of healthcare providers in educating the public appears limited [18], and there may be insufficient engagement from local media and advocacy groups [19].

Our findings are in line with previous studies that have also identified limited knowledge about hemophilia across various populations [15,16,20,21]. A study assessed the awareness of hemophilia in children among the Saudi population and found that 46.7% of participants were unaware of hemophilia. Additionally, 50% of them do not know about the disease's gender prevalence or whether it is hereditary or acquired, and around half were unaware that hemophilia is treatable or that bleeding episodes can be fatal. The observed low public awareness was comparable across all education groups, with no statistically significant differences [15]. Also, Naveed *et al.* [20] reported that 40% of the general population in Pakistan did not know about hemophilia, and 50% did not know that hemophilia is mainly hereditary. In Egypt, Mahmoud [21] showed that over half of the caregivers of children with hemophilia had inadequate knowledge about the condition. Almost half of the teachers of patients with hemophilia in Indonesia had poor knowledge about hemophilia [16].

Even studies involving patients with hemophilia have revealed inadequate knowledge. For instance, Karimi *et al.* [22] found that Iranian patients aged 8 to 37 years had a poor understanding of the condition. Similarly, Novais *et al.* [23] reported that both French patients with hemophilia and their informal caregivers lacked sufficient knowledge and practical skills related to managing the disease. Also, hemophilia carriers and their health care providers showed several knowledge gaps and challenges [24].

The knowledge gaps identified in this study have serious public health implications, including delayed diagnosis, increased risk of complications, and inadequate emergency response for individuals with hemophilia [13,25,26]. Misconceptions about the disease may also contribute to poor support of hemophilia patients [27]. These findings highlight the urgent need for targeted education and awareness campaigns to improve understanding, promote early intervention, and enhance overall care. Addressing this issue could significantly contribute to promoting early care- seeking behavior and ultimately improving the quality of life for affected individuals and their families. In this context, Phadnis and Kar [28] demonstrated significant improvement in Knowledge scores and health-related quality of life after an educational intervention. Cutica *et al.* [29] also declared a positive association between greater knowledge and the acceptability of hemophilia's new treatments, like gene therapy.

The results of the present study also showed that sex, age, and education level had no significant impact on knowledge about childhood hemophilia. The findings suggest that public education on childhood hemophilia should target all demographic groups of the general population. Nevertheless,

individuals who personally knew someone with hemophilia displayed significantly higher knowledge, suggesting that direct exposure to the condition is a key factor in increasing awareness. Therefore, integrating personal stories and patient experiences into awareness campaigns could be an effective strategy to enhance public understanding.

The study has some limitations that should be acknowledged before generalizing the results. Its cross-sectional design limits the ability to determine causal relationships or assess changes in knowledge over time. Additionally, the use of self-reported data may introduce bias. Non- response bias is another concern, as individuals with limited interest or awareness of health issues may have been less likely to participate.

CONCLUSIONS

The study highlights a substantial lack of public knowledge about childhood hemophilia in Tabuk City, Saudi Arabia. Nearly half of the respondents had no awareness of the condition, and only a small proportion demonstrated good understanding. The findings revealed widespread deficiencies in recognizing key aspects of hemophilia, including its inheritance, symptoms, severity, complications, and management. The high proportion of "Not know" responses across most knowledge items emphasizes the urgent need for targeted public education initiatives. "Such initiatives are crucial for improving early diagnosis, ensuring timely management, and enhancing health outcomes in children with hemophilia."

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